

MEDICALLY UNEXPLAINED SYMPTOMS

A Resource for Veterans, Service Members, and Their Families

Medically Unexplained Symptoms is a term used for persistent health symptoms which remain unexplained after a complete medical evaluation. It has been reported that vague or ill-defined health symptoms account for half of all outpatient visits and that one third of these symptoms remain unexplained after a thorough assessment (*Jackson, et al., 2005*). Although common, symptoms which remain unexplained for long periods of time even after a complete medical evaluation can be confusing and frustrating for both patients and providers. Sometimes there is a consistent clustering of the same or similar symptoms. When this happens, they are referred to as medically unexplained syndromes (MUS). A syndrome is a collection of signs and symptoms known to frequently appear together but without a known cause. Being given the diagnosis of an MUS can be a relief because you have a label— a diagnosis, but the key is how to effectively manage the multiple symptoms. This can be very challenging but will often lead to feeling better and being more in control of your health. This fact sheet gives an overview of three specific MUS's: Chronic Fatigue Syndrome, Fibromyalgia, and Irritable Bowel Syndrome and discusses things you can do to minimize the symptoms and improve your quality of life.

Chronic Fatigue Syndrome

Chronic Fatigue Syndrome (CFS) is a condition in which people have unexplained severe fatigue of at least 6 months duration, as well as a number of accompanying symptoms like muscle aches, sore throat, poor sleep, or problems with memory and concentration.

CFS is fairly common among the general population and has also been diagnosed among service men and women. A recent study showed that CFS was more common in Gulf War Veterans than non-Gulf War Veterans (*Eisen et al., 2005*). At this time, the exact cause for this is unknown.

There are no specific blood tests or medical procedures to diagnose CFS. The diagnosis can be given once other diseases, which can also cause fatigue, have been ruled out and the provider has determined that the patient meets the criteria for CFS. Thus CFS is considered a diagnosis of exclusion. There are a number of routine tests including blood work and a complete physical examination by a clinician that can effectively rule out most of the other major causes of fatigue and these must be done and be negative prior to being diagnosed with CFS. The good news is that this does not require years of endless invasive and extensive testing.

Treatment for CFS is based on individualized care plans. Therapies which may help CFS symptoms include: a program of graded aerobic exercise which involves slowly increasing physical activity, psychological therapies specifically designed to help people cope with chronic symptoms, and medications to address specific symptoms.

Clinical experience shows that with appropriate symptom management some patients improve. In general, people with CFS can experience both good periods – when symptoms seem to lessen or be more tolerable and bad periods when symptoms seem to worsen. It is important to know what your normal range of symptoms are. Clinical experience and research supports a “watchful waiting” attitude. If a symptom gets much worse than usual, it is probably a good idea to discuss it with your doctor. In general, regularly scheduled follow up visits are enough to discuss any new approaches to treatment or breakthroughs in the understanding of the syndromes.

For specifics about Chronic Fatigue Syndrome, you can visit the Center for Disease Control Web site at:

<http://www.cdc.gov/CFS/>

Fibromyalgia

Fibromyalgia (FM) is another MUS that is primarily characterized by diffuse pain and/or stiffness, and pain in multiple specific tender points. A diagnosis of FM is based on the patient's subjective symptoms of widespread pain and symptom severity. Pain must be present for greater than three months at the same level of intensity and the patient should not have a disorder that would otherwise explain the pain.

FM is a common condition that affects approximately 5% of the general population. It affects women more than men.

A study in Veteran populations showed that FM has been diagnosed more frequently in Gulf War Veterans compared to non-Gulf War Veterans (*Eisen, et al., 2005*). No known cause for FM has been identified.

Treatment focuses on reducing pain. Graded exercise therapy including paced activities like walking or biking is recommended and has been shown to improve the symptoms of FM. Medications are also used to reduce symptoms of FM.

If symptoms get much worse you should talk about them with your health care provider. Keep in mind that the symptoms of FM may alternate with periods of good health followed by periods when symptoms may flare up or worsen.

Irritable Bowel Syndrome

Irritable Bowel Syndrome (IBS) is an MUS that interferes with the normal functioning of the large intestine. It is characterized by a group of symptoms, including crampy abdominal pain, bloating, constipation, and diarrhea. IBS is considered a "functional bowel disorder" because it causes problems with the function, not the structure, of the bowel. This means that when samples of the bowel are looked at by colonoscopy or under a microscope they appear normal in patients with IBS, which is very different from patients with inflammatory bowel disease (Chron's Disease, Colitis, etc.) or cancer, which have markedly abnormal structures. IBS is the

most common functional gastrointestinal disorder that occurs worldwide. It is seen at rates ranging from 9-23%. IBS has also been diagnosed in the combat Veteran population.

IBS causes a great deal of discomfort and distress, but it does not permanently harm the intestines and does not lead to intestinal bleeding or to any serious disease such as cancer. To diagnose IBS, the provider will take a thorough history of the symptoms and of how often and for how long the symptoms have been occurring. The provider will use the history, and in some cases additional testing, to rule out other types of intestinal disorders, that would require different treatment.

Most people can control their symptoms with diet, stress management, and medications prescribed by their health care provider.

Treatments for Medically Unexplained Syndromes

The following treatments have been found to be helpful for many people who have medically unexplained symptoms such as chronic pain or persistent fatigue and/or syndromes (CFS, FM, IBS).

Graded Exercise

As with any new health regimen, you should first contact your health care provider and determine your exercise readiness.

A program of focused exercise is a valuable treatment available for someone with CFS or FM to help them improve their physical condition and their quality of life. People with pain and chronic fatigue should not overexert themselves, but should maintain a regular, balanced exercise program with the goal of gradually increasing physical activity. Stretching and flexibility are also very important for any exercise program, so be sure to include gradual stretching at the start and finish. Remember, if you feel too tired, or your symptoms get worse, take a day off and then restart your program at a slightly shorter duration or intensity and work

back up. Keeping an exercise record (date, duration of exercise, what you did and how you felt) can be helpful in modifying your exercise routine and in seeing how far you've come. Keeping active, both physically and mentally, may help alleviate some of your pain and your fatigue.

For more specific information on how to get started, please see our fact sheet on exercising to manage chronic pain and fatigue:

<http://www.warrelatedillness.va.gov/education/factsheets/exercise-to-manage-pain.pdf>

Psychological Therapies

Patients living with chronic fatigue, pain or gastrointestinal symptoms frequently benefit from cognitive-behavioral therapy (CBT) in order to help cope with and adjust to living with a chronic condition. CBT is a psychological therapy that emphasizes the important role of thinking in how we feel and behave. Goals include replacing unhealthy, negative beliefs and behaviors with healthy, positive ones that promote recovery and well being. CBT is often recommended in combination with other treatments and depends on a patient's symptoms, success with other treatments, etc.

This type of therapy teaches ways to better manage symptoms, and the stress of living with them. An individual works with his or her CBT mental health provider to set goals and work on strategies that can help with things such as pacing of everyday activity, improvement of sleep, exercise, use of social support, and daily practices such as relaxation.

Pharmacological Therapy

Pharmacologic therapy, also called drug therapy, should focus on reducing symptoms. There are different types of medications which may help a person dealing with CFS, IBS, and FM. It's important to remember that certain medications may not be appropriate for every patient. A health care provider will determine which medications may be right, taking into account medical history and current symptoms. These may include anti-depressants, non-steroidal anti-inflammatory drugs, and

stimulants. There are currently three medications that are FDA approved to specifically treat pain associated with fibromyalgia. These include Lyrica (pregabalin), Cymbalta (duloxetine), and Savella (milnacipran).

Types of medications often prescribed for IBS include anti-spasmodics, anti-diarrheal, and anti-depressant drugs as well as fiber supplements. In 2008, the FDA approved the use of the constipation drug Amitiza to treat irritable bowel syndrome with constipation in women aged 18 and older. In 2009, the drug Lotronex was approved for severe cases of diarrhea predominant IBS in women who haven't responded to other treatments. This drug must be prescribed by a gastroenterologist and is not approved for use by men.

If you feel like your symptoms may improve with the help of medication, speak to your health care provider about which medications may be appropriate.

Research

Ongoing research is constantly providing new information about the possible causes, diagnosis and management of Medically Unexplained Syndromes. If you have questions about research in these areas, it's important to use your health care provider as a resource. The internet also can provide a tremendous amount of information, but it's important to understand how the research has been conducted and its relevance to you. For more information about understanding how to interpret current research findings, please see our WRIISC fact sheet:

<http://www.warrelatedillness.va.gov/education/factsheets/how-to-interpret-research.pdf>

The following Web sites provide thorough information about current initiatives investigating MUS's:

- <http://www.cdc.gov/cfs/programs/index.html>
- <http://clinicaltrials.gov/ct2/results?cond=%22Fibromyalgia%22>
- <http://www.clinicaltrials.gov/ct2/results?term=irritable+bowel+syndrome>

Common Questions and Concerns

What is the difference between a syndrome and disease?

A syndrome is a collection of signs and symptoms known to frequently appear together but without a known cause. CFS, FM, and IBS are all syndromes. A disease is a known entity which has a recognized cause and usually a demonstrable cellular, tissue and/or organ abnormality with an identifiable group of signs and symptoms.

I have medically unexplained symptoms but have never been diagnosed with a "syndrome". What does that mean?

More important than the name of the syndrome is the fact that you have symptoms that need to be addressed. We know that patients who suffer from chronic fatigue and pain can at times feel better or worse. What is encouraging is that clinical experience shows that over the long term patients do not simply continue to get worse. If a symptom gets much worse than usual, it is probably a good idea to discuss it with your doctor. In general, regularly scheduled follow up visits are the right times to discuss any new approaches to treatment or breakthroughs in the understanding of the syndromes.

The diagnosis of a medically unexplained syndrome (CFS, FM, IBS) is based on a group of persistent and specific troublesome symptoms. Giving a name to a syndrome makes it easier to discuss the condition and to be able to investigate possible causes, the natural history or

course of the syndrome and how to treat it. However, the medical community (i.e. health care practitioners) does not universally recognize the existence of these syndromes. Unexplained symptoms are often seen in people following deployment, regardless of when or where deployed, but are also found in civilian populations.

It's important to realize that treatment and prognosis for medically unexplained symptoms versus a medically unexplained syndrome (CFS, FM, IBS) is often the same, with the focus on reducing symptoms and improving quality of life.

I've been struggling with unexplained syndromes for many years and I am not sure what to do to get the help I need?

It's important to address your symptoms and concerns with your health care provider. You can also discuss with your provider getting a referral to the War Related Illness and Injury Study Center (WRIISC). The WRIISC provides comprehensive medical evaluations for medically unexplained symptoms and focuses on providing a road map to help minimize impairments and improve overall quality of life.

Please visit our Web site:

<http://www.warrelatedillness.va.gov>

or call us at 1-800-248-8005 for more information on how to get a referral.